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BURDENS OF PRIMARY FAMILY CAREGIVERS OF ADULT SURVIVORS OF BRAIN INJURY

©

BY

AGNES MARIE MITCHELL

A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF NURSING.

FACULTY OF NURSING

EDMONTON, ALBERTA

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I was pleased to hear you found the CBI useful in your work.

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Mark Novak, Ph.D.
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I appreciate your interest in my work. Your project sounds quite interesting. I wish you luck.

Sincerely,

Leonard I. Pearlin

Leonard I. Pearlin
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DEGREE: Master of Nursing

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June 17, 1992

DEDICATION

To family caregivers of adult survivors of brain injury.

Burdens of Primary Family Caregivers of Adult Survivors of Brain Injury

Abstract

The purposes of this study were to measure the total amount of burden, identify different types of burden, and identify the variables associated with burdens experienced by caregivers of adult survivors of brain injury (BI). The sample consisted of 102 primary family caregivers from five brain injury support groups and respondents to advertisements in local city newspapers in Alberta.

The Family Caregiver Survey consisted of five scales. Four of these scales were from an instrument developed from Pearlin, Mullan, Semple, and Skaff (1990) that included: cognitive status scale, behavioral status scale, ability to perform activities of daily living (ADL) scale, and caregivers' perceived informal social support. Burden was measured by the Caregiver Burden Inventory (Novak & Guest, 1989a). As well, data included demographic characteristics of the survivors of BI and the primary family caregivers.

The level of burden experienced by the caregivers was moderately low at 33.2, on a scale of 0 to 100, with higher values reflecting high burden. Developmental burden was rated the greatest burden, and emotional burden was rated the lowest type of burden experienced by caregivers. Statistically significant correlations were found between total caregiver burden and the survivors' cognitive status, behavioral status, and ability to perform ADL, and the caregivers' perceived informal social support. Characteristics of the caregivers and length of time since the BI were not significantly correlated with caregiver burden. Using multiple regression analysis, one statistically

significant predictor was found for total caregiver burden, namely, the frequency of problematic behaviours on the part of survivors. The only statistically significant predictor of physical burden was caregivers' perceived informal social support.

ACKNOWLEDGEMENTS

I wish to express my gratitude to the many people who have contributed to the completion of this study. I would especially like to acknowledge Dr. Anita Molzahn, chairperson of my committee. She was always available to give expert guidance, and support. As well, Professor Marlene Reimer and Dr. Herbert Northcott provided valuable suggestions for the success of this project.

This research project would not have been possible without the cooperation from the directors and volunteers of the brain injury support groups. I am sincerely grateful to the caregivers who took the time to complete the surveys.

My educational journey started many years ago. I appreciate the support and encouragement from all my friends, colleagues, and co-workers.

My journey would not have been possible without the love, support, and humour from my parents, Margaret and James Mitchell. Words of wisdom were always appreciated from my sister in-law, Michele, my nephew, Bradley, my niece, Shannon, and my brothers, Vincent, John, Joe, David, and Dan.

Finally, financial support from the Alberta Association of Registered Nurses and the Alberta Foundation of Nursing Research is gratefully appreciated.

Table of Contents

I. Introduction 1

Problem 2

Purpose 3

Research Questions 3

Study's Framework 4

Research Hypotheses 5

Definition of Terms 6

II. Literature Review 8

Conceptualizing and Measuring Caregiver Burden 8

The Conceptual Definition of Burden 8

Measurement of Burden 9

Burden Associated with Various Conditions 14

Elderly Population 14

Dementia 15

Alzheimer's Disease 15

Stroke 16

Brain Injury 16

Correlates of Burden 18

Characteristics of Caregivers 19

Length of Time Caregiving 20

Cognitive Impairment of Survivors 20
Behaviours of Survivors' of BI 20
Deficits in Ability to Perform ADL 21
Social Support of Family Caregivers 22
Summary of Literature Review 23

III. Methodology 25
Sample 25
Data Collection Procedure 26
Instruments 28
Cognitive Status Scale 30
Behavioral Status Scale 30
Ability to Perform ADL Scale 33
Informal Social Support Scale 35
Caregiver Burden Inventory 38
Ethical Considerations 44
Data Analysis 44
Summary 45

IV. Findings 46
Characteristics of Sample 46
Characteristics of Caregivers 46
Characteristics of Survivors 46

Descriptive Statistics 48
Levels of Caregiver Burden 55
Predictors of Caregiver Burden 57
Relationships with Caregiver Burden 59
Summary 62

V. Discussion, Limitations, and Recommendations 63
Discussion 63
Unexpected Response 67
Limitations 68
Recommendations for Future Research 70

VI. Summary, Conclusions, and Nursing Implications 72
Summary of Findings 72
Conclusion 73
Implications for Nursing Practice 74

References 76

Appendix A 85

Appendix B 86

Appendix C 87

Appendix D 88

Appendix E 89

Appendix F 91

Appendix G 94

Appendix H 96

Appendix I 97

Appendix J 98

Appendix K 99

List of Tables

Table	Description	Page
3.0	Reasons for Excluding Surveys	27
3.1	Correlation Matrix: Items in the Cognitive Scale	31
3.2	Correlation Matrix: Dependent and Independent Variables Related to Caregiver Burden	32
3.3	Correlation Matrix: Items in the Behavioral Scale	34
3.4	Correlation Matrix: Items in the ADL Scale	36
3.5	Correlation Matrix: Items in the Perceived Informal Social Support Scale	37
3.6	Correlation Matrix: Items in the Time Dependency Burden Dimension	39
3.7	Correlation Matrix: Items in the Developmental Burden Dimension	40
3.8	Correlation Matrix: Items in the Physical Burden Dimension	41
3.9	Correlation Matrix: Items in the Social Burden Dimension	42
3.10	Correlation Matrix: Items in the Emotional Burden Dimension	43

4.0	Characteristics of Caregivers	47
4.1	Survivor's Place of Residence	49
4.2	Mean Scores of Independent Variables	50
4.3	Mean Scores of Items in the Cognitive Scale	52
4.4	Mean Scores of Items on the Behavioral Scale	53
4.5	Mean Scores of Items on the ADL Scale	54
4.6	Mean Scores of the Total Burden Scale and the Different Kinds of Burdens	56
4.7	Regression Model of Caregivers' Total Burden Scale	58
4.8	Regression Model of Caregivers' Physical Burden Dimension	60

I. Introduction

A brain injury (BI) is an unexpected and uninvited event that changes the personal interactions between the survivor and his or her family and friends forever. Family members most often assume the care and responsibility for survivors of BI (Baker, 1990; Brooks, Campsie, Symington, Beattie, & McKinlay, 1986, 1987; Campbell, 1988; DeJong, Batavia, & Williams, 1990; Jacobs, 1988; Kozloff, 1987; Rogers & Kreutzer, 1984). The care and responsibilities for survivors of BI results in burdens for family caregivers.

The burdens family caregivers carry are often heavy. Caregiver burden is a complex mixture of emotional, psychological, physical, financial, and social obligations and responsibilities for a family member or friend. Hence, burdens of caregivers of survivors with BI need to be understood so that nurses can anticipate, identify, and help caregivers' meet their own needs and the needs of survivors of BI.

BIs vary in degree of severity. Motor vehicle accidents (MVA), falls, occupational or recreational accidents, and physical assaults are the causes of most BIs. Some survivors of BI may experience loss of consciousness for several weeks or more, and others may not have experienced any loss of consciousness.

The number of survivors of BI has steadily increased over the years (Baker, 1990; Rimel, Jane, & Bond, 1990). In Canada, each year, 200 adults with traumatic BI are hospitalized per 100,000 population (Parkinson, Stephenson, & Phillips, 1985). Therefore, in Alberta, an estimated 4,860 new cases of traumatic BI are admitted to Alberta hospitals every year (Alberta Health, 1991). Traumatic BIs are two to three

times more common in males than in females (Rimel et al., 1990). Rimel et al. (1990) reviewed several studies that suggest BIs most often occur between the ages of 15 and 29 years, with the highest risk group between 15 and 19 years of age.

Survivors of BI may suffer from: immobility, cognitive disabilities, problematic behaviours, emotional instability, inability to perform activities of daily living (ADL), epilepsy, decreased social contacts, and personality changes (Brooks & McKinlay, 1983; DeJong et al., 1990; Fordyce, Rouche, & Prigatano, 1983; Lezak, 1978, 1987; Oddy & Humphrey, 1980). Hemiparesis, hemiplegia, partial or complete aphasia, ataxic gaits, dysarthria, and dysphagia are the possible physical problems that can occur after a BI. Physical problems of the survivors do not seem to be as burdensome as the emotional, cognitive, and behavioral problems (Brooks et al., 1987; Kay & Cavallo, 1991; Lezak, 1988; McKinlay, Brooks, Bond, Martinage, & Marshall, 1981). Many studies have documented the outcome of survivors' physical, emotional, social, cognitive, and behavioral status after BI (Bond, 1976; Lezak, 1978; Rappaport, Herrero-Backe, Rappaport, & Winterfield, 1989). Chronic problems evolve and are ongoing for survivors of BI.

Problem

Most survivors of BI are young adults, male, and are becoming productive members of society. The care and responsibility for the survivor of BI immediately affects the daily life of the family and particularly the primary family caregiver. For the remainder of this thesis, primary family caregivers will be referred to simply as

caregivers. The caregiver's future plans must be changed; care and responsibility for the survivor may become long term. Caregiver burden may limit the caregiver's freedom of action in their daily affairs. Considerable burden on the caregiver is a common outcome. Hence, in this study, several kinds of burdens experienced by caregivers of survivors of BI will be examined.

Purpose

The purposes of this study were to measure the total amount of burden, identify different types of burden, and identify the variables associated with burdens experienced by caregivers of adult survivors of BI.

Research Questions

1. How much burden and what type(s) of burden do caregivers of survivors of BI experience?
2. Is there a relationship between caregivers' characteristics (age, relationship, and place of residence) and the amount of burden of caregivers?
3. Is there a relationship between the length of time since the BI and the amount of total, time dependency, developmental, physical, social, and emotional burden of caregivers?
4. Is there a relationship between the cognitive and behavioral status of the person with a BI and the burdens of the caregivers?

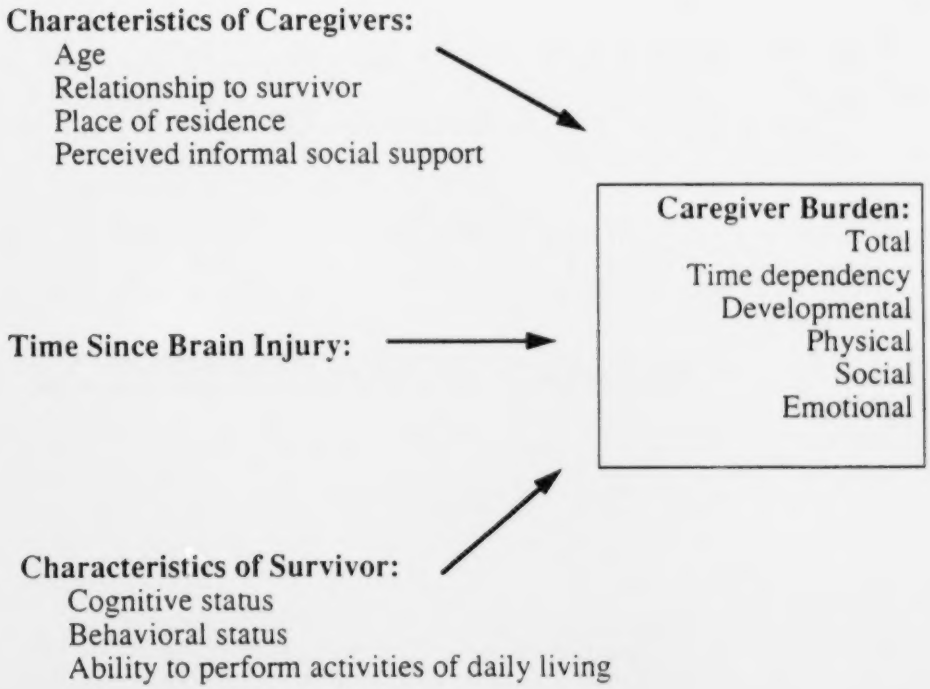
5. Is there a relationship between the BI survivors' inability to perform ADL and caregiver burden?

6. Is there a relationship between perceived informal social support and the burdens of the caregivers?

Study's Framework

Possible predictors of caregiver burden for this study are schematically diagrammed in Figure 1.

Schematic Representation of Predictors and Caregiver Burden



Research Hypotheses

This research tests the following hypotheses:

1. Caregivers' characteristics:

a) age of the caregivers is associated with total caregiver burden, with older caregivers demonstrating higher burden.

b) age of caregivers is associated with developmental burden, with younger caregivers demonstrating high developmental burden.

c) wives who are caregivers tend to have higher total caregiver burden, than do mothers.

d) high total caregiver burden is associated with living in the same residence as the survivor.

2. increased length of time since the BI is associated with high total caregiver burden.

3. low cognitive status is associated with high total caregiver burden.

4. increased frequency of the survivors' problematic behaviours is associated with high total caregiver burden.

5. the survivors' inability to perform ADL is associated with high total caregiver burden.

6. caregivers' increased perceived informal social support is associated with low total caregiver burden.

Definition of Terms

Caregiver: a person who identifies him/herself as the one who primarily provides care, support, and at various times is responsible for an adult survivor of a BI.

Total Caregiver Burden: is the complex mixture of psychological, physical, social and emotional obligations and responsibilities a caregiver has for a significant family member or friend as measured by the Caregiver Burden Inventory (CBI) (Novak & Guest, 1989a). The CBI includes the following five dimensions of caregiver burden:

Time Dependency Burden: restrictions on caregivers' own personal time every day.

Developmental Burden: restrictions on caregivers' related to a particular period of time in their lives.

Physical Burden: physical demands on caregivers attributed to caring for survivors of BI.

Social Burden: caregivers' interactions with other family members, co-workers, and friends.

Emotional Burden: caregivers' feelings towards survivors of BI.

Survivor: an adult who has sustained a BI after her or his sixteenth birthday as a result of a MVA, a work or a recreational related accident, or a violent act.

Brain Injury: occurs as the result of rapid movement of the brain within the skull at the time of forceful impact causing some degree of shearing or stretching of the brain tissue. Persons with progressive degenerative neurological conditions, cerebral

vascular accidents, brain tumours, or other congenital disorders are not included in this category.

Cognitive Status: the survivor's ability to think, communicate, and problem solve as measured by a modified cognitive status subscale of an instrument developed by Pearlin, Mullan, Semple, and Skaff (1990). Five aspects of cognitive ability, namely orientation, recent memory, remote memory, information processing, and concentration are included.

Behavioral Status: refers to those overt actions (behaviours) of the survivor that may or may not be socially inappropriate and/or problematic. Caregivers' assessment of survivors behavioral status is measured according to a modified subscale of the instrument developed by Pearlin et al. (1990).

Informal Social Support: the basic social needs of affection, approval, belonging, identity, and security that caregivers perceive from interactions with other family members and friends (Thoits, 1982). Informal social support is measured by a subscale of the instrument developed by Pearlin et al. (1990).

Summary

Understanding caregiver burdens may help nurses anticipate and perceive the needs of the caregivers of survivors of BI. The research questions and hypotheses listed in this chapter were generated in an attempt to describe and explain the burdens of caregivers of survivors of BI.

II. Literature Review

Introduction

Caregiving is a fertile ground for persistent stress, as family relationships change from an ordinary exchange of assistance among individuals to a relationship of extraordinary and unequal distribution of responsibilities (Pearlin et al., 1990). Since the mid 1950s and 60s burden has been studied in caregivers of persons suffering from mental disorders (Maurin & Boyd, 1990). In the late 1970s, burden research began with caregivers of people with Alzheimer's disease and dementia disorders (Zarit, Reeves, & Bach-Peterson, 1980), elderly persons (Archbold, 1980), and people with BI (McKinlay et al., 1981). For the purposes of this study, the literature review has been subdivided into the following areas: conceptualizing and measuring caregiver burden, burden associated with various conditions, and correlates of burden.

Conceptualizing and Measuring Caregiver Burden

The definition and measurement of burden is discussed in the following pages. Unidimensional, dichotomous, and multidimensional perspectives are reviewed.

The Conceptual Definition of Burden

In the literature, there is a confusing picture of the concept, burden, because there is inconsistency and a lack of conceptual clarity in the measurement of caregiver burden. Many different theoretical models (Biegel, Sales, & Schultz, 1991; Nolan, Grant, & Ellis, 1990; Montgomery, Gonyea, & Hooyman, 1985; Robinson, 1990;

Vitaliano, Russo, Young, Becker, & Maiuro, 1991) have been used. Conceptually, burden has been defined as the effect of caring for a person with physical, behavioral, or cognitive problems on family members (Bull, 1990; Livingston & Brooks, 1988; Nolan et al., 1990; Maurin & Boyd, 1990; Poulshock & Deimling, 1984). Caregiver burden has also been defined as physical, emotional, social, or financial problems or costs experienced by caregivers in relation to caring for an individual (Carlson & Robertson, 1990; George & Gwyther, 1986; Kosberg & Cairl, 1986; Printz-Feddersen, 1990). The distress produced by caregiving is described as caregiver burden by some researchers (Lawton, Kleban, Moss, Roving, & Glicksman, 1989). The different definitions of burden have led to many different ways to measure burden.

Measurement of Burden

Burden is most frequently operationalized as the caregivers' subjective perception of his/her emotional, physical, social, and financial status in relation to giving care to their relative (Klein, 1989; Livingston & Brooks, 1988; Novak & Guest, 1989b; Poulshock & Deimling, 1984; Printz-Feddersen, 1990; Zarit, Todd, & Zarit, 1986). The Burden Interview, an unidimensional scale, was developed by Zarit et al. (1980). This scale contains 29 items rated on a 5-point ordinal scale. Internal consistency reliabilities for the Burden Interview have been reported to be 0.79 (Novak & Guest; 1989b), and 0.91 (Vitaliano, Young, & Russo; 1991). Test-retest reliability (alpha = .71) of this scale is also high (Vitaliano, Young, & Russo, 1991). This tool has been modified several times and used with caregivers of individuals with

dementia (Zarit et al., 1986), caregivers of individuals with Alzheimer's disease (Novak & Guest, 1989b; Pratt, Schmall, Wright, & Cleland, 1985), and caregivers of individuals with a BI (Friss, Whitlach, & Yale, 1990). Modifications of the Burden Interview included decreasing the number of items to as few as eight and measuring the items dichotomously. The Burden Interview has been administered as an interview and as a self-administered questionnaire.

Another unidimensional, 7-point analogue scale measuring burden was used with caregivers of relatives of the BI population (Brooks et al., 1986, 1987; McKinlay, et al., 1981). The scale ranged from "I feel no strain as a result of the changes in my spouse/relative" to "I feel severe strain as a result of the changes in my spouse/relative" (McKinlay et al., 1981). The responses on this scale were collapsed into three categories: low, medium, and high burden scores. Interrater reliability was established between two raters for 20 interviews. The reliability and validity of items on the scale were not reported.

A dichotomous conceptualization of burden, namely subjective and objective burden was used by Montgomery et al. (1985). Subjective burden, defined as the caregiver's attitudes or emotional reactions to the caregiving experience, was measured by 13 items on a 5-point scale adapted from Zarit's et al. (1980) 29 item Burden Interview. Objective burden, defined as the extent of disruptions or changes in various aspects of the caregiver's life and household was measured by nine items on a 5-point inventory. Alpha reliability of the subjective and objective inventories were reported to be 0.86 and 0.85, respectively.

Robinson (1983) developed a tool called the Caregiver Strain Index. It was developed for a population of elderly caregivers who cared for someone with heart disease or after hip surgery. The Index contained 13 items measured dichotomously. Internal consistency was reported at .86 and construct validity was supported in relation to care recipient characteristics, caregivers' subjective views of the caregiving situation, and the emotional health of the caregivers. Adapting this scale to a different population of caregivers warrants careful consideration (Vitaliano, Young, & Russo; 1991).

The Cost of Care Index developed by Kosberg and Cairl (1986) measures several dimensions of the cost of caregiving. Developed as a case management tool, the Cost of Care Index measured the following five dimensions: personal and social disruptions, physical and emotional health, value, care recipient as provocateur, and economic costs. Internal consistency was reported to be 0.91. The tool was developed to facilitate clinical decisions for family caregivers caring for elderly relatives rather than to specifically measure family caregiver burden.

The Screen for Caregiver Burden was developed specifically for spouse caregivers of Alzheimer's patients by Vitaliano, Russo, Young, Becker, and Maiuro (1991). This tool includes 25 items measuring objective burden and subjective burden. Objective burden is measured as the frequency of caregiving experiences, and subjective burden is rated on a 4-point scale in relation to the distress of each experience (Vitaliano, Young, & Russo, 1991). The lowest internal consistency reported was .85 and construct validity was supported by relationships of care

recipient behaviours and cognitive functioning with objective burden and caregiver distress, and personality variables with subjective burden. Limitations of this tool include the specificity of content to spouses and inclusion of subjective statements in the objective score (Vitaliano, Young, & Russo, 1991).

Poulshock and Deimling (1984) measured burden in two different dimensions. Burden was explained as disruptive behaviour burden and ADL impairment burden. Caregivers rated each ADL on a 3-point scale as tiring, difficult, or upsetting. Caregivers rated the three mental impairment indicators on a 3-point likert-type scale as not at all, somewhat, or a great deal. It was found that disruptive behaviour burden was a mediating variable between the two independent variables (elder's disruptive behaviour and caregiver's depression), and negative impact on family relationships. ADL impairment burden was a mediating variable between two independent variables (elders' ADL impairment and caregivers' depression), and caregiver social activity restrictions. The two dimensions of burden were associated directly with tasks of physical dependence and mental incapacity. The dependent variables (negative impact on family relationships and caregiver social activity restrictions) were considered subjective burdens or outcomes of caregiving. The dependent variables were measured on a 19 item scale. Eleven items reflected the negative changes in elder-caregiver/caregiver-family relationships resulting from caregiving. Factor loadings for these items ranged from 0.46 to 0.75.

Correlations between burden measures demonstrated independence of burden associated with the elder's ADL impairment and the burden associated with the

elder's mental impairment (Poulshock & Deimling, 1984). Family relationships and caregiver social activity restrictions, as the two dependent variables, were significantly correlated with the measures of impairment and burden with a few exceptions. This study suggests that burden has several underlying dimensions that are correlated with mental impairment and disruptive behaviours. ADL impairment burden is measured on a nominal scale making it difficult to assess psychometric properties (Vitaliano, Young, & Russo, 1991). Another problem with these burden dimensions is that the concept, burden, is both a mediating variable and a dependent variable.

Novak and Guest (1989a) also suggest that burden is multidimensional; they developed a tool called the Caregiver Burden Inventory (CBI). The items for the CBI were developed from the experiences of caregivers of individuals with Alzheimer's disease and the literature on burden. The dimensions of burden are: time dependence, emotional, social, developmental, and physical burdens. The CBI has practical applications, is easy to administer, and has good psychometric properties which are described later.

In summary, there are a diverse group of scales available to measure caregiver burden. However, comparing studies of burden is problematic because there is no consistency in the conceptualization or the measurement of burden (Poulshock & Diemling, 1984).

Burden Associated with Various Conditions

The study of burden associated with various conditions is examined. Also, the significant variables that are associated with burden are addressed.

Elderly Population

Montgomery et al. (1985) found that younger caregivers with low incomes experienced greater subjective burden. Objective burden was accounted for by three significant variables. These were tasks designated as type seven by the authors (walking, transportation, errands), tasks designated as type two by the authors (nursing care, bathing, dressing), and the number of people who assisted the caregiver.

Poulshock and Deimling (1984) considered burden as a mediating variable. The sample consisted of 307 spouses, with similar numbers of men and women, and 307 adult children, mostly daughters. Other variables that were considered were elder's age, caregiver's age, socioeconomic status, physical health, and depression, but only the latter displayed a consistent relationship with the two dimensions of burden and dependent variables of family relationships and caregivers' social restrictions. First, they found that almost half of the variance of caregiver social activity restrictions was explained by caregivers' depression, elders' ADL impairment, and ADL impairment burden. Second, they found that half of the variance in negative impact on elder and caregiver family relationships was explained by caregivers' depression, elders' disruptive behaviour, and disruptive behaviour burden.

Dementia

Carlson and Robertson (1990) measured subjective and objective burden in 38 (19 male and 19 females) spouses of partners who were diagnosed with dementia. It was found that measures of psychosocial and physical impairment of spouses and caregivers were not related to objective burden. A significant positive relationship between length of time since diagnosis and objective burden existed only with female caregivers. Level of psychosocial impairment was significantly related to female caregivers' subjective burden. Length of time since diagnosis accounted for 23% of the variance in female caregiver subjective burden, and the partner's psychosocial impairment accounted for 22%.

In an exploratory study, Gilhooly (1984) examined the impact of caring for individuals with dementia on spouses. Interestingly, it was found that the longer the duration of caregiving, the higher the caregivers' morale and the better the caregivers' mental health.

Alzheimer's Disease

Pratt et al. (1985) examined the relationships of coping strategies used by 240 caregivers of relatives with Alzheimer's disease with the caregiver's sense of burden. The unidimensional Burden Interview by Zarit et al. (1980) was used. They found that three internal coping strategies (confidence in problem-solving, reframing the problem, and passivity) and two external coping strategies (spiritual support and extended family) were significantly related to caregiver burden scores. The caregivers' age, sex, income, education, or relative's place of residence were not

significantly related to burden scores. Burden scores were significantly related to the caregiver's health status.

In Novak's and Guest's (1989b) study of 30 caregivers of spouses with Alzheimer's disease, significant correlations were found between burden and functional decline (.38), strength of desires (.68), and change in happiness (.62). Length of time of caregiving was not significantly correlated with burden. The independent variables of functional decline, length of care, and time since diagnosis accounted for 32% of the variance in the dependent variable, burden. Perceived happiness and caregiver desires for social activities accounted for another 45% of the variance.

Stroke

Fitzgerald (1989) conducted a qualitative study with eight caregivers of spouses who had experienced a stroke. She identified four outcomes of caregiving and measured the intensity of these outcomes over time (average length of time in caregiving role at second interview was 11.5 months). These four outcomes were: decreased physical and emotional health, changed role, loss of freedom and social activities, and marital discord. Marital discord increased and became more intense over time.

Brain Injury

Subjective and objective burden in 55 relatives was examined 3, 6, and 12 months after the survivor's BI (McKinlay et al., 1981). The mean score on a 7-point analogue subjective burden scale remained the same at 3, 6, and 12 months (mean =

3.5). Increased duration of post-traumatic amnesia (PTA) was significantly related to high burden at 3 months but there were no significant relationships between PTA and burden at 6 and 12 months. Mental and behavioral changes in the survivor were associated with a significant increase in subjective burden.

Five years later, 42 relatives out of 55 in the previous study were recontacted and the survivors and relatives were reinterviewed (Brooks et al., 1986). Subjective burden experienced by relatives had significantly shifted towards high levels at 5 years. The increased burden could be predicted, as it was in the first year, by the behavioral, personality, and affective changes in the survivor.

Brooks et al. (1987) found that 89% of 134 relatives of BI survivors reported high or medium levels of burden up to 7 years after the injury. Burden experienced by relatives was grouped into low, medium, and high burden levels. Severity of the BI, as measured by duration of PTA, was not significantly related to the relatives' burden scores. Family members reporting low burden levels were found to have relatives with fewer behavioral changes. However, a high number of behavioral changes was not always associated with a high burden level. Greater emotional changes in the survivor were associated with higher levels of burden. The relationship with the survivor was examined, and there was no significant difference between burden levels experienced by parents and spouses.

Brooks and McKinlay (1983) had 55 relatives of survivors of BI rate the premorbid and current personalities of the BI survivors at 3, 6 and 12 months. A personality adjective checklist was used. An increase in negative scores, reflecting

changes in survivors' personalities, was associated with relatives' high subjective burden. High burden scores at 12 months post injury were associated with emotional behaviours (quick temper, irritable, changeable), reduction in energy (lifeless, listless), immaturity, and unreasonableness. Relatives perceiving high burden scores thought that the survivors' personality had changed 92%, whereas relatives who perceived their burden to be low to medium judged their survivors' personality had changed 50%. Survivors' reports of increased symptomatic complaints accounted for more than 50% of the variance in the relatives' perceived burden at 3, 6, and 12 months after injury (Livingston & Brooks, 1988).

Burden was measured by the Burden Interview developed by Zarit et al. (1980) in 60 relatives caring for survivors of BI in California (Friss et al., 1990). This was a subgroup of a much larger study. High levels of burden were reported by 63% of these relatives. Since this was largely a descriptive study, no predictors of burden were reported.

Correlates of Burden

The key variables that have been studied in relation to burden are briefly discussed. They include: characteristics of caregivers, length of time caregiving, cognitive impairment of survivors, behaviours of survivors' of BI, deficits in ability to perform ADL, and informal social support of caregivers.

Characteristics of Caregivers

The following is a profile of the typical caregiver from a large sample in a recent California study: a woman under 50, living with her brain-injured husband or son, working outside the home to make ends meet, who is depressed and feeling highly burdened (Family Survival Project, 1990). The majority of subjects in Acorn's (1991) and Campbell's (1988) studies were mothers. Brooks et al. (1987) found the greatest numbers of caregivers were wives (53) and mothers (27).

Brooks et al. (1987) found no differences in the distribution of burden scores in parents and spouses. They stated that clinical wisdom suggests that wives cope less well than mothers because the nature of the burden is quite different for a wife (change in psychosexual functioning, a variety of role changes) than for a mother (reversion to previous roles). However, differences in burden scores between mothers and wives were insignificant.

Rosenbaum and Najenson (1976) studied wives of soldiers who had spinal cord injuries and wives of soldiers who sustained BI. Wives of BI soldiers reported greater and more disturbing changes in their everyday lives than the wives of the paraplegic soldiers. Wives of BI husbands also reported higher levels of depression. Wives attributed strong feelings of loneliness and social isolation to their BI husbands who had become self-oriented and childish since their BI.

Enright (1991), who studied caregivers of brain-impaired adults (mostly degenerative brain disorders) found that spousal caregivers devote large amounts of

time to caregiving. Husbands spent no less time than wives, but husbands received more help than other caregivers (wives, daughters, mothers, or sons).

Length of Time Caregiving

Caregivers of survivors of BI may face decades of caring because BI occur most frequently with people in their early 20s, and life expectancy is not shortened like that of individuals who have cancer or those who develop a brain disorder much later in their life. Brook et al. (1987) found that levels of burden remain high for at least 7 years after the BI. Most other studies are cross-sectional in design, and burden is not measured over time (Friss et al., 1990).

Cognitive Impairment of Survivors

Brooks (1990) summarized the research and literature since the 1980's on cognitive deficits of individuals with BI. Several descriptive and correlational studies have been reported in which cognitive deficits are examined from the caregiver's perspective (Brooks et al., 1986, 1987; McKinlay et al., 1981; Rappaport et al., 1989). Brooks et al. (1986) found that relatives reported that memory problems had increased from the first to the fifth year post injury, but that they were not troublesome on a daily basis. Memory difficulties were reported as a major problem for 15% of 26 caregivers (Rappaport et al., 1989).

Behaviours of Survivors' of BI

In the clinical literature, behaviours that have been identified as a direct result of BI include impatience, an inability to learn from experience, anxiety, depression, withdrawal, aggression, changed temperament, decreased initiation, poor self-control,

and attention seeking (Jacobs, 1991; Levin et al., 1987; Lezak, 1988; Rosenthal & Bond, 1990). A small sample of 14 caregivers reported that behavioral changes were most stressful to them (Campbell, 1988). Caregivers of survivors of BI in a large study in California reported that the survivors' stubborn, uncooperative, or impulsive behaviours were most problematic (Friss et al., 1990).

Descriptive and predictive studies conducted from 3 months to 7 years post BI have demonstrated that behavioral problems of survivors of BI have a significant effect on the caregivers (Brooks et al., 1986, 1987; Brooks & McKinlay, 1983; Jacobs, 1988; Livingston, Brooks, & Bond, 1985; Mauss-Clum & Ryan, 1981; McKinlay et al., 1981). These behaviours include threats or actual violence against the relative, suspicious behaviours, childishness, talking excessively, withdrawing from social interaction, and impatience.

Deficits in Ability to Perform ADL

McNeny (1990) comprehensively reviewed the clinical components of the survivor's possible deficits in ability to perform ADL. Friss et al. (1990) reported the following problems with ability to perform ADL that 94 caregivers of survivors of BI experienced: managing money (83%), doing household chores (71.9%), needing constant supervision (70%), dressing (58%), bathing/showering (55.2%), and feeding self (45.8%). It is not clear whether impairments in ability to perform ADL contribute to burden in caregivers of survivors of BI. A lack of consistency exists between research studies in items found in scales measuring cognitive status, behavioral status, and ability to perform ADL.

Social Support of Family Caregivers

Excellent literature reviews regarding the social support problems associated with BI on the survivor's family exist (Florian & Katz, 1991; Livingston, 1990; Williams & Kay, 1991). Nursing research studies have been mostly descriptive and have identified and measured the needs of survivors' families. These studies have numerous methodological weaknesses such as lack of reliability or validity of instruments and small sample sizes (Baker, 1990; Campbell, 1988; Mathis, 1984; Mauss-Clum & Ryan, 1981).

It has been demonstrated that strong family support has a positive impact on the survivor (Mauss-Clum & Ryan, 1981; McKinlay et al., 1981; Oddy & Humphrey, 1978; Rogers & Kreutzer, 1984). The research suggests that as time passes, the social network of the survivor's family decreases in size and increases in density (degree of commitment in a relationship) (Kozloff, 1987). The social network has been found to play a significant role in stress reduction among caregivers (George & Gwyther, 1986; Gilhooly, 1984). Yet in another study, caregivers who reported that they had an individual who acted as a confidante did not have lower caregiver burden (Brooks et al., 1987). This contradiction in findings may be from cultural differences or in the measurement of social support. Friss et al. (1990) found that 43.2% of caregivers of survivors of BI ($n = 95$) received formal social support and 42.6% received informal social support. Caregivers' age, gender, health, income, race, and ethnicity were not related to caregivers' receipt of either formal or informal support.

Support groups for survivors, as well as for relatives and friends, are numerous. In three exploratory, descriptive nursing studies, the usefulness of BI support groups was examined and in two of these studies the needs of the caregivers were also addressed (Acorn, 1991; Campbell, 1988; Williams, 1990). The results indicated that the purpose of the membership was primarily to gain knowledge in the area of BI. Williams (1988) reported that support groups were the greatest help for people who had experienced BI in the family more than 12 months before, and for caregivers who were less than 45 years old. It may be that the support groups reduce caregiver burden, but research has not been conducted in this area.

Summary of Literature Review

In summary, burden is a complex concept that has been operationally defined unidimensionally, dichotomously, and multidimensionally. Burden has been measured in caregivers of individuals with a variety of medical conditions. Burden measured in caregivers of survivors of BI has been reported to remain high for up to 7 years after the BI (Brooks et al., 1987). Characteristics of caregivers have not generally been found to predict caregiver burden. The survivors' behavioral status, cognitive status, and the inability to perform ADL, the caregivers' needs, and formal and informal social support are important variables to consider in relation to the caregiver's burden. Understanding the complexity of caregiver burden is necessary for nurses to anticipate and perceive the needs of caregivers. For this reason, this research study

is of particular value in understanding the burdens of caregivers, and the variables that are associated with that burden.

III. Methodology

Introduction

In this descriptive correlational study, the relationships between caregiver burden and a number of independent variables were explored through the use of a survey. The independent variables included: length of time since BI, characteristics of the caregivers (age, relationship to the adult survivor, and place of residence of the BI survivor), ability to perform ADL, cognitive status, behavioral status of the survivor, and caregivers' perceived informal social support. The dependent variable of interest was caregiver burden. Caregiver burden is divided into five kinds of burden: time dependence, developmental, physical, social, and emotional burden. In this chapter, the sample, data collection procedure, instruments, hypotheses, operational definitions, ethical considerations, and data analysis are discussed.

Sample

A convenience sample of 102 caregivers of adult survivors of BI participated in the study. Respondents were obtained by contacting five BI support groups and through newspaper advertisements. According to Cohen (1977) approximately 110 caregivers were required to attain a power of 0.8, considering the eight independent variables, and a medium effect size. The four criteria for inclusion in the study were: 1) The caregiver was over eighteen years of age, resided in Alberta, and had the most frequent contact of any family member/friend to the BI survivor.

2) The caregiver could read and understand English.

3) The caregiver cared for an adult survivor who experienced a BI after his/her sixteenth birthday.

4) The adult survivor's BI was the result of a MVA, work, recreational or violent accident.

A total of 370 surveys were sent out. The membership to some BI support groups included volunteers and professionals, and it was not always possible to prevent the surveys from being sent to these people. A number of information letters and surveys were returned because of incorrect addresses or because the recipients of the surveys were not caregivers. The approximate overall response rate was 45%. The study's sample response rate after exclusion of a number of surveys was 28%. In Table 3.0, the numbers and reasons why surveys were excluded are described.

Data Collection Procedure

Two methods were used to access the caregivers. First, members of 5 out of the 11 BI support groups across Alberta participated in this study. The BI support groups included: the Northern Alberta Brain Injury Society; Southern Alberta Brain Injury Society; Central Alberta Brain Injury Society; Grande Prairie Brain Injury Society; and Lloydminister and Area Brain Injury Society. The BI support groups mailed all correspondence to the caregivers to provide anonymity. The first

Table 3.0

Reasons for Excluding Surveys

Reasons for Excluding Surveys	n
Causes of BI:	
Aneursyms	19
Strokes	5
Brain Tumours	4
Arteriovenous Malformations	3
Encephalitis	2
Arrests (Cardiac, Respiratory)	2
Other causes	4
Survivors under the age of 16 years at time of BI	11
Survivors responded to the survey	7
Persons other than the primary family caregiver responded to the surveys	4
Caregivers who reported the deaths of survivors with BIs	2
Total	63

mailing consisted of a written introductory letter to their members (see Appendix A) explaining the study and notifying them that a survey would be mailed to them in two weeks. One support group attached the letter to their regular newsletter. The survey followed, along with a self-addressed stamped envelope. A follow up reminder and thank you letter (see Appendix B) was mailed 2 to 3 weeks after the survey was sent. This letter reminded them to complete the survey if they had not done so.

The second method involved advertising in the local newspapers of Edmonton, Red Deer, and Grande Prairie (Appendix C). Caregivers were invited to participate in this study. The caregiver made contact by phone or mail to the researcher. If the caregiver phoned, the researcher ensured that the caregiver met the inclusion criteria and sent the survey and information letter with a self-addressed stamped envelope. Caregivers who responded by mail were sent an introductory letter (see Appendix D) explaining the study with the survey and the self-addressed envelope. A follow up reminder and thank you letter (see Appendix B) was mailed 2 to 3 weeks after the introductory letter and survey. Only 6 respondents out of a dozen enquiries from the newspaper advertisements met the inclusion criteria for the study.

Instruments

The survey included sections on demographic characteristics of the adult survivor of BI and the caregiver (see Appendices E and F), cognitive status of the adult survivor of BI (see Appendix G), behavioral status of the adult survivor of BI (see Appendix H), the adult survivor's ability to perform ADL (see Appendix I),

perceived informal social support of the caregiver (see Appendix J) and the CBI (see Appendix K). Face and content validity of the instruments were established with the assistance of four experts who have knowledge, experience, and involvement with caregivers of adult survivors of BI. Each expert was asked whether each question was meaningful, clear, relevant, appropriate, and acceptable for inclusion in the survey. Attainment of a level of 75% agreement was the necessary criterion for the item to be included. Minor changes were made to some items such as: including a definition of coma, differentiating between kind and amount of work of the survivor after the BI, and clarifying of three items reflecting short term memory on the cognitive status scale. The content experts agreed that the survey, as a whole, adequately sampled the universe of caregiver burden for this population.

The cognitive status, behavioral status, ability to perform ADL, and perceived informal social support scales were parts of an instrument developed by Pearlin et al. (1990). Permission was received from the authors to use these scales. The instrument was developed from interviews with caregivers of spouses with Alzheimer's disease. These scales were generated from transcripts of interviews using open-ended questions; conceptual themes were identified and structured questions were formed. Pretests and revisions of questions resulted in an instrument with reasonable psychometric properties. Each scale and the CBI will be discussed individually.

Cognitive Status Scale

The cognitive status scale includes 20 items (refer to again to Appendix G). Twelve items were added to Pearlin et al.'s (1990) original eight items to cover five aspects of cognition that included orientation, recent memory, remote memory, information processing, and concentration. The 20 items were ordinally scored from 1 to 5. A high score on this scale indicated high cognitive ability. Pearlin et al. (1990) reported the Cronbach's alpha of the cognitive status subscale as .86, and for this study, it was .97.

A correlation matrix was generated for the items of the cognitive status scale (see Table 3.1). All correlations between these items were statistically significant ($p < .01$). The magnitude of the correlations ranged from .36 to .93. Using the multitrait method procedure, it was noted that interitem correlations within the cognitive scale were higher than the correlations between the cognitive status scale and the other independent variables. For example, the correlation between stating name and stating day of the week (items in cognitive status scale) was .75 and and between cognitive status and perceived social support was .02 (refer to Table 3.1 and Table 3.2 again).

Behavioral Status Scale

Five items were added to the original 14 items of Pearlin et al.'s (1990) behavioral status scale. The five new items were specific to behaviours of survivors of BI, and were derived from the literature. These items were: displays childish

Table 3.1

Correlation Matrix: Items in the Cognitive Status Scale

	Items	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1	State his/her name	1.0																			
2	State the day of the week	.75	1.0																		
3	State the year	.78	.93	1.0																	
4	Name the prime minister of Canada	.62	.74	.66	1.0																
5	Remember a short message	.57	.73	.65	.72	1.0															
6	Remember past day	.51	.75	.67	.68	.85	1.0														
7	Remember to complete task	.54	.71	.64	.69	.76	.84	1.0													
8	Remember address	.74	.72	.73	.72	.65	.61	.65	1.0												
9	Recognize people	.36	.47	.39	.50	.53	.49	.49	.52	1.0											
10	Find his/her way around the block	.59	.70	.69	.65	.67	.67	.78	.72	.40	1.0										
11	Understand simple instructions	.45	.52	.43	.50	.68	.63	.62	.56	.58	.51	1.0									
12	Speak sentences	.73	.68	.68	.65	.57	.46	.52	.65	.34	.55	.48	1.0								
13	Solve a simple problem	.61	.75	.68	.74	.79	.73	.73	.71	.50	.69	.72	.68	1.0							
14	Follow two requests without help	.39	.61	.52	.66	.75	.72	.66	.61	.61	.57	.74	.51	.79	1.0						
15	State his/her desires or wants	.60	.67	.59	.66	.71	.60	.66	.67	.55	.63	.65	.77	.79	.74	1.0					
16	Tell the time	.71	.72	.76	.50	.47	.49	.56	.63	.45	.68	.53	.65	.66	.51	.61	1.0				
17	Think clearly	.50	.59	.49	.60	.76	.70	.71	.61	.63	.59	.72	.48	.78	.79	.73	.52	1.0			
18	Keep his/her attention on an activity for 15 minutes	.46	.61	.51	.57	.71	.66	.69	.46	.60	.54	.67	.44	.64	.66	.63	.53	.68	1.0		
19	Start at the number 100 and subtract 7, and 7 again, and 7 again	.46	.60	.58	.60	.70	.65	.66	.57	.44	.69	.58	.44	.76	.68	.59	.52	.67	.65	1.0	
20	Add the numbers 26 and 50	.61	.65	.67	.57	.61	.61	.65	.69	.42	.73	.58	.55	.69	.58	.61	.68	.59	.56	.79	1.0

** all correlations in this scale were statistically significant ($p < .01$)

Table 3.2

Correlation Matrix: Dependent and Independent Variables Related to Caregiver Burden

	Items	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1	Caregiver age	1.0													
2	Relationship to survivor	-.59**	1.0												
3	Residence of survivor	-.25*	.50**	1.0											
4	Cognitive Status	-.30**	.14	.29*	1.0										
5	Behavioral Status	.11	-.20	-.13	.29*	1.0									
6	Perceived informal social support	-.02	.18	.03	.02	.06	1.0								
7	ADL	-.25	.04	.20	.76**	.30*	-.07	1.0							
8	Total burden	-.04	-.16	-.11	-.43**	-.43**	-.34**	-.56**	1.0						
9	Time dependency burden	.08	-.09	-.11	-.69**	-.42**	-.23*	-.72**	.68**	1.0					
10	Developmental burden	.09	-.20	-.08	-.41**	-.30*	-.24*	-.45**	.87**	.49**	1.0				
11	Physical burden	.02	-.17	-.14	-.36**	-.31**	-.28**	-.32*	.83**	.47**	.73**	1.0			
12	Social burden	.17	.04	-.15	-.15	-.21	-.28*	-.23	.72**	.25*	.54**	.50**	1.0		
13	Emotional burden	.06	.03	.06	-.14	-.35**	-.13	-.23	.57**	.23*	.44**	.21*	.41**	1.0	
14	Time since BI	.46**	-.08	.04	-.14	-.06	-.06	-.18	-.07	-.01	-.02	-.19	-.03	.17	1.0

*p= < .05

**p= < .01

behaviour, becomes tired very easily, has no control over alcohol intake, complains about physical condition, and complains about living situation. Caregivers rated the frequency of each behaviour on an ordinal, 4-point likert-type scale. A lower score on the behavioral status scale indicated that problematic behaviours occurred more frequently. Pearlin et al. (1990) reported a Cronbach's alpha of .79 for the behavioral status scale, and for this study the alpha was .88.

A correlation matrix was generated between all of the items in the behavioral status scale (see Table 3.3). The magnitude of the interitem correlations ranged from -.14 to .70. The correlations between the behavioral status scale and the other independent variables ranged from .05 to .44. Using the multitrait method procedure it was noted that interitem correlations within the behavioral scale were generally higher than the correlations between the behavioral scale and the other independent variables. For example, the correlation between hiding belongings and repeating questions (items measuring behavioral status) was .45 while the correlation between behavioral status and perceived informal social support was .06 (refer to Tables 3.2 and 3.3 again).

Ability to Perform ADL Scale

No alterations were made to the ADL subscale developed by Pearlin et al. (1990). The scale consists of 15 items that were scored on a 4-point likert-type scale ranging from (1) completely to (4) not at all. A low score on the ADL scale indicated that the survivor was dependent on the caregiver for ADL. The Cronbach's alpha for the ADL scale remained the same as reported in previous work at .91 (L.

Table 3.3

Correlation Matrix: Items in the Behavioral Status Scale

	Items	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1	Keep you up at night	1.0																	
2	Repeat questions/stories	.30**	1.0																
3	Try to dress the wrong way	.27*	.49**	1.0															
4	Have a bowel or bladder "accident"	-.14	-.03	.10	1.0														
5	Hide belongings and forget about them	.27*	.45*	.38**	.06	1.0													
6	Cry easily	.31**	.22*	.14	.01	.41**	1.0												
7	Act depressed or down hearted	.44**	.42**	.23*	.06	.44**	.42**	1.0											
8	Cling to you or follow you around	.24*	.33**	.26*	.08	.36**	.09	.35**	1.0										
9	Become restless or agitated	.46**	.38**	.16	.09	.60**	.31**	.62**	.38**	1.0									
10	Become irritable or angry	.43**	.46**	.19	.11	.44**	.34**	.61**	.39**	.70**	1.0								
11	Swear or use foul language	.39**	.40**	.18	-.04	.46**	.29**	.38**	.15	.56**	.66**	1.0							
12	Become suspicious	.30**	.29**	.25*	.09	.48**	.23*	.22*	.31**	.36**	.46**	.44**	1.0						
13	Threaten violence towards others or yourself	.36**	.23*	.06	-.06	.40**	.26*	.18	.30**	.47**	.44**	.51**	.45**	1.0					
14	Display childish behaviour	.23*	.52**	.25*	.13	.30**	.10	.30**	.26*	.31**	.41**	.36**	.17	.19	1.0				
15	Becomes tired very easily	.34**	.35**	.29**	.05	.36**	.23*	.49**	.25**	.57**	.48**	.33**	.14	.15	.29**	1.0			
16	Have no control over alcohol intake	.17	.08	.20	.29**	.13	.01	.13	.15	.12	.08	.14	.33**	.09	.09	.09	1.0		
17	Complain about their physical condition	.43**	.29**	.13	-.11	.26*	.15	.44**	.26*	.49**	.43**	.27**	.13	.28**	.25*	.39**	-.10	1.0	
18	Complain about their living situation	.20	.34**	.23*	-.04	.41**	.24*	.37**	.11	.40**	.45**	.56**	.29**	.32**	.28**	.27**	.09	.41**	1.0
19	Show sexual behaviour or interests at the wrong time or place	.21*	.17	-.05	.18	.16	-.04	.02	-.05	.05	.24*	.29**	.26*	.06	.30**	.09	.28**	.02	.16

*p= < .05
**p= < .01

Pearlin, personal communication, September, 1991).

A correlation matrix was generated between all items on the ADL scale (see Table 3.4). All items were positively correlated with each other. The interitem correlations ranged from .23 to .90. Referring again to Table 3.2 and Table 3.4, the correlations between the ADL scale and the other independent variables were generally lower than the interitem correlations of the ADL scale. For example, the correlation between the ADL scale and the perceived informal social support scale was -.07.

Informal Social Support Scale

The informal social support scale included eight items scored on an ordinal 4-point likert-type scale. No changes were made to this scale. A high score on this scale indicated that the caregivers perceived strong informal social support from other family members or friends. Pearlin et al. (1990) reported an alpha reliability of .87; for this study, the Cronbach's alpha was .89.

An interitem correlation matrix was generated for the caregivers' perceived informal social support scale (see Table 3.5). All correlations were statistically significant and ranged from .24 to .79. Using a multitrait method procedure it was noted that the interitem correlations of the perceived informal social support scale were higher than the magnitude of the correlations between the perceived informal social support scale and the other independent variables (refer again to Table 3.2). For example, the correlation between perceived informal social support and cognitive status was .02.

Table 3.4

Correlation Matrix: Items in the ADL Scale

	Items	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1.	Eating	1.0													
2.	Bathing	.61**	1.0												
3.	Going to the bathroom	.50**	.80**	1.0											
4.	Dressing/undressing	.58**	.76**	.84**	1.0										
5.	Brushing teeth/hair	.63**	.81**	.76**	.79**	1.0									
6.	Handling money	.50**	.61**	.45**	.47**	.61**	1.0								
7.	Getting in/out of bed	.44**	.73**	.90**	.86**	.68**	.40**	1.0							
8.	Moving around the house	.48**	.77**	.90**	.89**	.75**	.41**	.89**	1.0						
9.	Driving or taking the bus	.40**	.51**	.36**	.35**	.48**	.50**	.33**	.42**	1.0					
10.	Going for a walk	.47**	.53**	.55**	.37**	.48**	.51**	.42**	.49**	.67**	1.0				
11.	Taking medications	.56**	.75**	.64**	.63**	.74**	.68**	.51**	.62**	.64**	.70**	1.0			
12.	Using the phone	.54**	.69**	.62**	.67**	.75**	.62**	.57**	.74**	.66**	.67**	.71**	1.0		
13.	Doing housework	.56**	.56**	.37**	.35**	.52**	.59**	.35**	.31**	.51**	.62**	.59**	.47**	1.0	
14.	Getting going in an activity	.53**	.52**	.36**	.42**	.55**	.56**	.43**	.40**	.50**	.45**	.58**	.49**	.77**	1.0
15.	Cooking/preparing food	.45**	.52**	.31**	.31**	.44**	.53**	.23*	.25*	.60**	.51**	.64**	.38**	.66**	.59**

*=p< .05
**=p< .01

Table 3.5

Correlation Matrix: Items in the Perceived Informal Social Support Scale

	Items	1	2	3	4	5	6	7	8
1	There is really no one who understands what I am going through	1.0							
2	The people close to me let me know that they care	.44**	1.0						
3	I have people in whose opinions I have confidence	.37**	.61**	1.0					
4	I have someone who I feel I can trust	.34**	.52**	.70**	1.0				
5	I have people in my life who make me feel good about myself	.31**	.50**	.64**	.79**	1.0			
6	I have at least one friend or relative I can really confide in	.24*	.37**	.48**	.68**	.71**	1.0		
7	I have at least one friend or relative I want to be with when feeling down or discouraged	.27**	.39**	.53**	.60**	.61**	.67**	1.0	
8	I have people around me who help me to keep my spirits up	.33**	.61**	.63**	.68**	.78**	.58**	.68**	1.0

*p= <.05

**p= <.01

Caregiver Burden Inventory

Burden was measured by the CBI developed by Novak and Guest (1989a) (see Appendix K). This scale included 24 items measured on a 5-point ordinal, likert-type scale. Items were scored from 0 to 4: strongly agree, agree, no opinion, disagree somewhat, and strongly disagree. This scale was then recoded so that an increase in scores reflected a greater burden. The concept, caregiver burden, is divided into five dimensions: time dependence, developmental, physical, social and emotional burden. Novak and Guest (1989a) reported internal consistency reliability coefficients (alpha) of the five dimensions of caregiver burden as .85, .85, .86, .73, and .77 respectively. In this study, the reliability coefficients (alpha) for the five dimensions of burden were as follows: time dependency .85, developmental .87, physical .87, social .82, and emotional .87. The Cronbach's alpha for the total scale was .92.

Interitem correlation matrices were generated for each dimension of caregiver burden (refer to Tables 3.6, 3.7, 3.8, 3.9, 3.10). Moderate correlations were evident between each of the items within the burden dimensions. These ranges were: time dependency (.32 to .75), developmental (.48 to .70), physical (.45 to .74), social (.27 to .68), and emotional (.47 to .75). Correlations between each of the burden dimensions and the total burden scale ranged from .21 to .87 (refer again to Table 3.2). Note also, that in Table 3.2, the correlations between the independent variables and the dependent variables were generally low and ranged from -.59 to .20.

Table 3.6

Correlation Matrix: Items in the Time Dependency Burden Dimension

	1	2	3	4	5
1. My relative needs my help to perform many daily tasks.	1.0				
2. My relative is dependent on me.	.66**	1.0			
3. I have to watch my relative with many basic functions.	.67**	.55**	1.0		
4. I don't have a minute's break from my caregiving chores.	.73**	.46**	.62**	1.0	
5. I feel that I am missing out on life.	.47**	.32**	.56**	.35**	1.0

**$p < .01$

Table 3.7

Correlation Matrix: Items in the Developmental Burden Dimension

	1	2	3	4	5
1. I feel that I am missing out on life.	1.0				
2. I wish I could escape from this situation.	.63**	1.0			
3. My social life has suffered.	.50**	.48**	1.0		
4. I feel emotionally drained due to caring for my relative.	.51**	.57**	.70**	1.0	
5. I expected that things would be different at this point in my life.	.51**	.61**	.63**	.64**	1.0

**p<.01

Table 3.8

Correlation Matrix: Items in the Physical Burden Dimension

	1	2	3	4
1. I'm not getting enough sleep.	1.0			
2. My health has suffered.	.64**	1.0		
3. Caregiving has made me physically sick.	.45**	.71**	1.0	
4. I'm physically sick.	.74**	.74**	.60**	1.0

**p<.01

Table 3.9

Correlation Matrix: Items in the Social Burden Dimension

	1	2	3	4	5
1. I don't get along with other family members as well as I used to.	1.0				
2. My caregiving efforts aren't appreciated by others in my family.	.68**	1.0			
3. I've had problems with my marriage.	.48**	.49**	1.0		
4. I don't do as good a job at work as I used to.	.27**	.33**	.45**	1.0	
5. I felt resentful of other relatives who could but do not help.	.60**	.57**	.45**	.37**	1.0

**p<.01

Table 3.10

Correlation Matrix: Items in the Emotional Burden Dimension

	1	2	3	4	5
1. I feel embrassed over my relative.	1.0				
2. I resent my relative.	.60**	1.0			
3. I feel uncomfortable when I have other friends over.	.75**	.52**	1.0		
4. I feel angry about my interactions with my relative.	.47**	.60**	.49**	1.0	
5. I feel ashamed of my relative.	.64**	.66**	.68**	.58**	1.0

**p < .01

Ethical Considerations

The study followed the ethical standards of the Canadian Nursing Association (1983). Ethical approval was obtained from the Ethics Review Committee of the Faculty of Nursing at the University of Alberta and the board or persons responsible for the selected BI Support Groups. Participation of caregivers was voluntary. Consent was assumed when caregivers mailed back responses voluntarily. The researcher assured caregivers of anonymity in the initial information letter. The names, addresses, and telephone numbers of the caregivers belonging to a BI Support Group were unknown to the researcher. Mailings were done from the offices of the BI support groups, and subjects were instructed not to include their names. Caregivers who responded from newspaper ads had their names, addresses, and phone numbers locked in a cabinet and kept separate from their surveys. All reports related to the study will use a summary of the pooled responses. At no time will it be possible to identify either individual caregivers or survivors of BI.

Data Analysis

Descriptive statistics (central tendency and dispersion) are reported for most variables. A correlation matrix was generated between scores for all variables. Multiple regression analyses were conducted, using caregiver burden as the dependent variable. Scores were obtained for each subscale as well as for the overall total burden score, and scores for each dimension as well as the total score were used as dependent variables. Demographic characteristics (caregivers' age, caregivers'

relationship to survivors, and residences of caregivers to survivors), time since BI, ability to perform ADL, behaviour and cognitive status of survivor, and caregivers' perceived informal social support were included in each equation as independent variables.

Summary

A cross-sectional correlational descriptive survey design was used to examine total caregiver burden and five different kinds of burden. The convenience sample consisted of 102 caregivers of survivors of BI who responded to advertisements or returned a mailed survey. The survey included demographic characteristics of the survivors and the caregivers, and five instruments. Ethical considerations and data analysis were discussed. Findings are described in Chapter IV.

IV. Findings

In this chapter, characteristics of the sample, and descriptive statistics for each of the scales are provided. Levels and predictors of caregiver burden are discussed. This is followed by presentation of findings of the relationships with caregiver burden, in the order of the research questions.

Characteristics of Sample

Characteristics of Caregivers

A total of 102 caregivers took part in the study. The majority of caregivers were female (86%), 52.5% were mothers, and 27.3% were wives (see Table 4.0). The average age of the caregivers was 50 years (SD=12.5), with a range from 23 through 79 years. The mean number of years of education was 13.4 (SD=2.9). Gainful employment was held by 51% of the caregivers; 37.3% worked fulltime and 12.1% worked part-time (refer again to Table 4.0). Household incomes of the caregivers were relatively high, with 54% earning equal to or greater than $31,000 a year. A little more than half of the caregivers lived with the survivors in the same residence (refer again to Table 4.0). The majority of caregivers (66% of n=97) did not have anyone else to help them care for their survivor on a regular basis.

Characteristics of Survivors

A total of 102 survivors with BI were described by their caregivers. As expected, 72% of the survivors were male and 28% were female. The mean age of

Table 4.0

Characteristics of Caregivers

Characteristic	n	%
Gender: female	86	86.0
male	14	14.0
Relationship to survivor:		
mother	52	52.5
father	6	6.1
wife	27	27.3
husband	8	8.1
sister	4	4.0
grandmother	1	1.0
other	1	1.0
Marital Status:		
married	76	75.2
common-law	1	0.9
single	1	0.9
divorced	9	8.9
widowed	12	11.9
separated	2	1.9
Lives with survivor in same residence:		
yes	55	54.5
no	46	45.5
Job other than caring for survivor:		
yes	51	51.0
no	49	49.0
Fulltime	37	37.3
Part-time	12	12.1
Not applicable	50	50.5

the survivors was 35 years, with a range from 17 through 74 years. The mean length of time since the BI was 91.8 months (7.7 years), with a range from 3 through 416 months (SD=77.9). Coma was experienced by 85% of the BI survivors. The mean length of time in a coma was 46.8 days, (SD=59), with a range from 1 through 360 days. The causes of the survivors' BI were: MVA (73.1%), accidents at work (16.1%), accidents during recreational activities (5.3%), falls (3%), and violent acts (2.1%). MVA included car, motorcycle, and pedestrian accidents. Seizures had occurred in 40% of the survivors since the time of the BI.

The majority of the survivors (99% of n=92) were admitted to acute care hospitals and 58% (n=101) were later transferred to rehabilitation hospitals. Caregivers reported that 55% of the survivors lived with them, and the remaining survivors were living independently, living independently with assistance, were hospitalized, or were living with others (see Table 4.1). Only 36.3% of the survivors returned to work and very few survivors returned to the same kind (10%) or amount (10%) of work they had prior to the BI.

Descriptive Statistics

A high score on the cognitive status scale reflected a high cognitive ability. The mean score on this scale was moderately high at 80.2 (possible range 20 to 100) (see Table 4.2). Therefore, the caregivers' perceptions were that the survivors' cognitive ability was fairly high. Scores on the items relating to recent memory (remember a short message, remember events of past day, remember to complete

Table 4.1

Survivor's Place of Residence

Residence	n	%
living with caregiver	54	54.6
living independently	10	10.1
rehabilitation hospital	10	10.1
living independently but with assistance	9	9.1
long term hospital	8	8.1
living with others (group home, another family)	4	4.0
acute care hospital	4	4.0
Total	99	100.0

Table 4.2

Mean Scores of Independent Variables

Scales	n	Possible Range	Observed Range	Mean	SD
Survivor's status:					
cognitive status	79	20-100	20-100	80.2	20.2
behavioural status	76	19- 76	35- 76	64.8	9.6
ability to perform ADL	55	15- 60	15- 60	48.7	11.4
Caregivers:					
perceived informal social support	93	8- 32	11- 32	24.5	4.7

task) were the lowest of the five aspects of the cognitive status scale (see Table 4.3). Items of concentration/attention (subtracting, thinks clearly, attention on an activity for 15 minutes) and two items of information processing (solve a simple problem, follow two requests without help from caregiver) were rated the next lowest on the cognitive status scale.

A low score on the behavioral status scale reflects a high frequency of problematic behaviours. The mean score on the behavioral status scale was moderately high at 64.8 (possible range 19 to 76) indicating that the problematic behaviours were not overly frequent (refer again to Table 4.2). The most problematic behaviours were: becomes tired very easily, becomes irritable or angry, repeats questions or stories, becomes restless and agitated, acts depressed or downhearted, and complains about their physical situation (see Table 4.4).

A high score on the ADL scale reflects greater independence in the survivors' ability to perform ADL. The average score on this scale was fairly high at 48.7 (possible range of 15 to 60). The items on the ADL scale with the lowest means (i.e., that the survivor was dependent on others for) were: cooking and preparing food, getting going in an activity, driving or taking a bus, handling money, doing housework such as sweeping the floors and taking medications (see Table 4.5).

A low score on the informal social support scale reflects that the caregivers perceived that they had low informal social support. The average score on the informal social support scale was high at 24.5 (SD=4.7) with a possible range from 8 to 32 (refer to Table 4.2).

Table 4.3
Mean Scores of Items in the Cognitive Status Scale
(n ranged from 93-101)

Items	Mean	SD
Orientation		
state his/her name	4.6	1.1
state the day of the week	4.1	1.4
state the year	4.3	1.3
name prime minister of Canada	3.9	1.5
Recent Memory		
remember a short message or phone call	3.6	1.4
remember what he/she has done in the past day	3.3	1.4
remember to complete a task	3.5	1.3
Remote Memory		
remember his/her address	4.3	1.3
recognize people that he/she knows	4.4	1.0
find his/her way around the town block or farm yard	4.0	1.5
Information Processing		
understand simple instructions	4.1	1.0
speak sentences	4.2	1.3
solve a simple problem	3.8	1.3
follow two requests without help from caregiver	3.8	1.3
state desires or wants	4.1	1.3
tell the time	4.6	1.1
Concentration/Attention		
think clearly	3.7	1.1
keep their attention on an activity for 15 minutes	3.8	1.2
start at the number 100 and substract 7, and 7 again, and 7 again	3.4	1.5
add the numbers 26 and 50	4.0	1.4

Table 4.4

Mean Scores of Items on the Behavioral Status Scale
(n ranged from 89-94)

Items	Mean	SD
keep you up at night	3.7	0.8
repeat questions/stories	2.9	1.2
try to dress the wrong way	3.8	0.6
have a bowel or bladder accident	3.8	0.7
hide belongings and forget about them	3.5	0.8
cry easily	3.8	0.6
act depressed or downhearted	3.1	1.0
cling to you	3.5	0.9
become restless or agitated	3.0	1.0
become irritable or angry	2.9	1.0
swear or use foul language	3.2	1.1
become suspicious or believe someone is going to harm him/her	3.7	0.8
threaten violence towards others or yourself	3.8	0.7
display childish behaviour	3.3	0.9
becomes tired very easily	2.4	1.2
have no control over alcohol	3.9	0.4
complain about their physical condition	3.1	1.1
complain about their living situation	3.4	1.0
show sexual behaviour at wrong time	3.8	0.7

Table 4.5

Mean Scores of Items on the ADL Scale (n ranged from 70-85)

Items	Mean	SD
eating	3.2	1.1
bathing/showering	3.2	1.1
going to the bathroom	3.6	1.0
dressing/undressing	3.5	1.0
brushing teeth/hair	3.5	1.0
handling money	2.7	1.1
getting out of bed	3.5	1.1
moving around the house	3.6	1.0
driving or taking the bus	2.7	1.3
going for a walk in the neighbourhood	3.4	1.1
taking medications	3.0	1.3
using the telephone	3.4	1.1
doing housework like sweeping the floors	2.8	1.2
getting going in an activity	2.6	1.1
cooking/preparing food	2.5	1.2

Levels of Caregiver Burden

The scores on Novak and Guest's (1989a) CBI could range from 0 to 100; the observed range was 0 to 80 with high scores indicating high burden. The mean total caregiver burden was moderately low at 33.2 (see Table 4.6). Developmental burden had the highest mean score (8.3) indicating the greatest type of burden (refer again to Table 4.6). Unexpectedly, emotional burden had the lowest mean score (3.1) indicating the least burden (refer again to Table 4.6).

The first research question addressed how much burden and what kinds of burden were experienced by the caregivers. A high level of burden was determined by dividing the possible range of the scores of each of the dimensions and the total CBI in half. The higher scores were considered to be high burden. For example, high total caregiver burden was all those caregivers who scored more than or equal to 51 (possible range was 0 to 100). As well, for each of the dimensions, the possible range was 0 to 20 so that the numbers of caregivers who scored more than or equal to 11 were considered to have high burden. High total burden was experienced by 25.7% of the caregivers. High burden scores experienced by caregivers for each kind of burden were: 41.% developmental burden, 32% physical burden, 29.6% time dependency burden, 24% social burden, and 9.5% emotional burden.

Table 4.6

Mean Scores of the Total Burden Scale and the Different Kinds of Burdens

Burden Scales	n	Possible Range	Observed Range	Mean	SD
total	70	0-100	0-80	33.2	20.8
time dependency	88	0- 20	0- 20	7.5	5.3
developmental	84	0- 20	0- 20	8.3	5.8
physical	92	0- 20	0- 20	7.0	6.0
social	87	0- 20	0- 20	7.2	5.3
emotional	95	0- 20	4- 20	3.1	4.5

Predictors of Caregiver Burden

The caregivers' perception of their burden and different kinds of burden were examined using a series of multiple regression equations. Separate equations were used for total burden and each kind of burden. All the independent variables were entered into each equation, using a forced entry procedure in SPSSx. These included length of time since the BI, caregivers' age, relationship to survivor, place of residence, and perceived informal social support, and survivors' cognitive status, behavioral status, and ability to perform ADL. The nominal variables, caregivers' relationship to survivor and survivor's place of residence were treated as dummy variables. These two variables were dichotomized, with 0 as mothers and 1 as wives, and 0 as caregiver not living with survivor and 1 as caregiver living with survivor.

The results of each regression equation were examined for significant predictors. Only reduced equations with significant predictors are reported. The reduced regression model explaining caregivers' total burden is shown in Table 4.7. The reduced equation, includes only one significant independent variable that explained 18.6% of the variance of total caregiver burden. A one unit increase on the behavioral status scale resulted in a predicted .952 unit decrease in total caregiver burden.

For the regression equations with the dependent variables, time dependency, developmental, social, and emotional burden, no significant predictors were found. This was attributed to the amount of missing data. Using listwise deletion of missing variables, if one item in a scale was not scored then that eliminated the whole scale

Table 4.7

Regression Model of Caregivers' Total Burden Scale

Variable	b		standard error	standardized b
Behavioral status	-.952***		.271	.431
Constant	6.311		17.66	
R^2=.186	ANOVA	df	SS	MS
	Regression	1	4347.22	4347.22
	Residual	54	19017.40	352.17

F = 12.344 sig = .0009

***p<.001

from the regression equation. Pairwise deletion of missing variables was also attempted. Although a few additional degrees of freedom were added, very few differences were found in statistically significant predictors.

With physical burden as the dependent variable, the model with all independent variables explained 63.6% of the variance. The reduced regression equation for explaining physical burden is shown in Table 4.8. A one unit increase in the caregivers' informal social support resulted in a -.362 unit predicted reduction of physical burden. Caregivers' informal social support only explains 7.8% of the variance in physical burden. The difference in significant findings was attributed to the amount of missing data and the different numbers of variables used in the equations when they were reduced.

Relationships with Caregiver Burden

A correlation matrix between all independent and dependent variables in the equations was generated (refer again to Table 3.2). There was not a problem with multicollinearity because the independent variables were not highly intercorrelated. Scatter plots were examined for curvilinear relationships between the dependent and independent variables. No curvilinear relationships existed. The zero-order correlations are addressed according to the order of the hypotheses outlined in chapter one.

The first hypothesis had three parts, each one associating a caregiver characteristic to total caregiver burden. There were no significant relationships

Table 4.8

Regression Model of Caregivers' Physical Burden Dimension

Variable	b	standard error	standardized b
perceived informal social support	-.362**	.135	-.279
Constant	15.789	3.368	

R^2 = .078

ANOVA	df	SS	MS
Regression	1	248.393	248.393
Residual	85	2941.621	34.607

F = 7.177 sig = .0089

**p < .01

between caregivers' age and total caregiver burden (r=-0.4) or caregivers' age and developmental burden (r=-.09). As well, eta statistics (nonparametric correlation) were generated between the nominal variables, relationship to survivor and total caregiver burden, and residence of caregiver to survivor and total caregiver burden. Using an eta statistic, no significant relationships were found.

The second hypothesis was not supported. Length of time since the survivors' BI was not significantly related to with total caregiver burden (r=.07).

The third hypothesis survivors' cognitive status was significantly ($p<.01$) related to total caregiver burden (r=.43). Cognitive status was also significantly ($p<.01$) related to time dependency burden (r=.69), developmental burden (r=.41), and physical burden (r=.36).

The fourth hypothesis was also supported; that is, the survivors' behavioral status was significantly ($p<.01$) related to total caregiver burden (r=.44). Behavioral status of survivors' was also significantly ($p<.01$) related to time dependency burden (r=.42), developmental burden (r=.30), physical burden (r=.31), and emotional burden (r=.35).

With respect to the fifth hypothesis, survivors' inability to perform ADL was significantly ($p<.01$) related to total caregiver burden (r=.56). Time dependency, developmental, and physical burdens were also significantly related to the survivors' inability to perform ADL (r=.72, r=.45, r=.32 respectively).

In relation to the sixth hypothesis, caregivers' informal social support was found to be significantly ($p<.01$) related to total caregiver burden (r=.34). As well,

caregivers' informal social support was significantly ($p < .05$) related to time dependency burden ($r = .23$), developmental burden ($r = .24$), social burden ($r = .28$), and physical burden ($r = .28$).

Summary

Descriptive statistics were reported. Levels of total caregiver burden and each type of burden were described. Behavioral status of survivors' explained 18.6% of the variance in total caregiver burden. Informal social support of the caregivers' explained only 7.8% of the variance in physical burden. Statistically significant correlations supported the hypotheses linking caregiver burden with survivors' cognitive status, behavioral status, ability to perform ADL, and caregivers' informal social support.

V. Discussion, Limitations, and Recommendations

This chapter includes the discussion of the findings in the order of the research questions. Unexpected response to the initial information letter from survivors and caregivers, limitations of the study and recommendations for future research are also discussed.

Discussion

The first research question addressed the amount of burden and the kinds of burden experienced by caregivers. The level of burden in this study was lower than expected. Only one quarter of the caregivers experienced high levels of burden. These results are similar to those found in a study of caregivers of impaired elderly (Zarit et. al., 1980). However, Brooks et al. (1986, 1987) and Friss et al. (1990) found that at least half or more of the caregivers of survivors of BI experienced high levels of burden. Those samples were from Scotland and the United States. Different health care systems, sociodemographics, and access to resources may explain some of the differences. It is also possible that caregivers who were most burdened did not respond to the questionnaire. There may also be other characteristics of caregivers or survivors of BI in this study that differed from those of other studies. However, it is difficult to compare findings when different scales are used.

In this current study, it was found that 41% of the caregivers experienced high levels of developmental burden. Novak and Guest (1989a) found that developmental

burden was highly correlated with depression in caregivers. Similarly, caregivers' feelings of depression were found to be related to the various measures of burden in a study by Poulshock and Diemling (1984).

In this study, 32% of the caregivers were experiencing high levels of physical burden. Although caregivers' health status was not examined, in another study, health status of the caregivers of individuals with Alzheimer's disease was found to be significantly related to caregiver burden (Pratt et. al., 1985). Caregivers in the study of Pratt et. al. (1985) were, on average 61.3 years old. In another study, the health of caregivers' (who were on average 67.5 years old) and wives of individuals with degenerative brain disorders were also significantly related to objective burden (Robinson, 1990). In this current study, the caregivers were younger and caring for survivors of BI who were almost all younger than themselves. It may be important to examine health status of caregivers of BI survivors in another study.

In this study, no significant relationships were found between the caregivers' characteristics (age, relationship, and place of residence) and the measures of burden. These results are similar to those found in other studies in which caregiver characteristics were examined in relation to burden (Brooks et al., 1987; Pratt et. al., 1985). In contrast, Montgomery et al. (1985) found that age (median was 56 years) and income (median was $20,000) of caregivers of elderly relatives were the best predictors of subjective burden.

In relation to the second question, length of time since the BI was not significantly related to caregiver burden. This was similar to a study of caregivers of

individuals with Alzheimer's disease in which burden was also unrelated to length of time since diagnosis (Novak & Guest, 1989). Carlson and Robertson (1990) found that the length of time since diagnosis of dementia was significantly related to the wives' objective burden but not to the husbands' subjective or objective burdens or wives' subjective burden. Length of time since BI may not have been significant in this study because the caregivers indicated a high amount of informal social support and it is suggested that caregivers may have accepted the survivors' outcomes to some degree.

In relation to the third question, significant relationships were found between the survivors' low cognitive status and high levels of total, time dependency, developmental, and physical caregiver burden. These results are similar to those of Brooks et al. (1987) who reported that cognitive status (language and memory) was significantly related to relative's burden. Other studies to date, have measured memory, language, or concentration separately rather than in one cognitive status scale. For the most part, descriptive rather than inferential statistics have been used.

It was also found that a higher frequency of problematic behaviours was significantly related to high levels of total, time dependency, developmental, physical and emotional burdens. These results are consistent with those of other studies of caregivers of survivors of BI (McKinlay et. al., 1981; Brooks et. al., 1986, 1987). In this current study, behavioral status of survivors was a significant predictor that explained 18.6% of the variance in total caregiver burden. This is similar to the findings of Livingston and Brooks (1988) who reported that survivors' symptomatic

complaints (behaviour) accounted for more than 50% of the variance in the relative's perceived burden.

The survivors' inability to perform ADL was also significantly related to high levels of total, time dependency, developmental, and physical caregiver burden. The variable, inability to perform ADL approached significance as a predictor of total caregiver burden, in this current study. The inability of survivors to perform ADL is an important variable to consider in the study of caregiver burden. Descriptive studies have taken this variable into consideration, but no other studies to date have used this variable as a predictor of burden.

In relation to the sixth question, caregivers' perceptions of informal social support were found to be significantly related to high levels of total, time dependency, developmental, physical, and social caregiver burden. These results are consistent with other studies of social support and burden in caregivers of mentally impaired elderly relatives (Zarit, et. al., 1980). George and Gwyther (1986) found that social support was significantly related to caregiver well-being in family caregivers of demented adults. Gilhooly (1984) found that caregivers' dissatisfaction with the help received was associated with low morale and poor mental health in caregivers of impaired elderly. In constrast, Robinson (1990a) found that nonassertive caregivers had lower subjective burden and less available social support. In the current study, one may postulate that caregivers who experience high levels of burden can tolerate their daily experience if they perceive they have informal social support. However, one needs to be cautious in comparing levels of burden and the different independent

variables across studies because almost every study reviewed has measured or operationalized the concepts of burden, and other independent variables differently.

Unexpected Response

After the initial 250 information letters were sent out to three of the BI support groups, it was most interesting to note that approximately 10% of the recipients called the researcher or the researcher's supervisor within the first week. The enquiries ranged from survivors wanting to tell their stories, to enquiring about the availability of resources for them to access. Some survivors insisted that they were responsible for themselves and did not have or need a caregiver. Several recipients wanted to clarify who was to complete the survey. A few caregivers thought too much time had passed since their relative's BI to remember what the caregiving experience had been like. Some caregivers and survivors offered their help, and some called simply to convey their thanks for interest in the area.

One survivor and one caregiver actually arrived at the University wanting to personally speak to the researcher's supervisor or the researcher about their experiences. A few caregivers called to report that their family member had died or had committed suicide. The number of phone inquiries was unexpected but proved to be important, particularly for the survivors who wanted to tell their stories of successful recovery. These inquiries suggest that there are many unmet needs in this population that need to be addressed both in clinical programs and research.

Limitations

The convenience sampling technique used in this study limits the generalizability of the findings. The sample is not necessarily representative of all caregivers of survivors of BI. Caregivers who do not belong to BI support groups may be different than those that do. Also, people who responded to the study may differ from those who did not (e.g., in terms of burden or other important variables). This convenience sample probably represented the middle class of society, as demonstrated by the level of education and yearly income. Random sampling techniques would have been extremely difficult, as the only other way to access caregivers of survivors of BI would have been to review years of medical records in several hospitals. Advertising in the local newspapers of several cities in Alberta yielded a very poor response, and those who did respond may not necessarily be representative of the entire population.

This cross-sectional study does not look at caregiver burden over time. A longitudinal study may identify particularly difficult times that the caregiver goes through, such as times when the survivors are transferred to a rehabilitation hospital, discharged from institutions, or when (and if) the survivor tries independently living. Even in this cross-sectional study, it was evident that caregivers and their survivors were going through periods of adjustment. For example, one caregiver reported that he/she had the survivor home on weekends and plans to have him/her home fulltime; another survivor had just moved into an independent living arrangement. Unforseen problems may occur with each new transition. Burden or different kinds of burden

may peak just at the beginning of a transition period to a new environment, and maybe affected by different levels of formal and informal social supports may fluctuate.

Several questions in the survey could have been worded differently to cause less confusion. The options to some questions were not mutually exclusive. For example, several caregivers marked two causes of BI, like MVA and work related accident. The order of the questions could have been taken in to consideration. For example, caregivers' characteristics could be asked before the survivors' characteristics. Also, the survey could have ended on a positive note, rather than on items measuring emotional burden.

The findings and conclusions are limited because of lack of availability of data from the surveys returned. It was estimated that 110 caregivers would be required to have a power of .80 for the regression equations, but only 102 respondents fit the sample criteria. Power was achieved in the reduced regression equations. When the dependent variable was total caregiver burden the power was .81. Power was .93 when physical burden was the dependent variable. Furthermore, it is estimated that 80% of the surveys were not completely filled out, resulting in considerable missing data. Hence, the regression equations, for the most part, were insignificant.

Financial burdens were not specifically addressed in this study. Loss of employment for caregivers, loss of income for survivors, lack of support in receiving workmen's compensation, lack of resources for home care services, and the long term nature of supporting someone are a few of the financial problems identified by the

caregivers. In written comments, a few caregivers mentioned difficulty accessing information from health care professionals, not knowing the resources available to them, and the stress associated with receiving hopeless evaluations from health care professionals. These are other areas of burden that were not addressed in this study.

In retrospect, the study measured the negative aspects of informal caregiving and did not address the benefits caregivers derived from caring for their loved ones. Several caregivers stated they derived a greater meaning from life and that their personal life plans had changed positively because of this experience of informal caregiving. The reciprocity of support in relationships between of the survivor and the caregiver was not addressed, nor was the burden experienced by other family members examined. This study also did not consider situations where more than one person shared the caregiving of survivors (i.e. couples caring for an adult).

Not all possible predictors of burden were addressed in this study. Other possible predictors of burden are health status of the caregiver, change in personality of survivor, caregivers' intrinsic qualities that are brought to the caregiving situation (Brooks et al., 1987), the premorbid relationship between the caregiver and survivor, survivors' and caregivers' premorbid characteristics, and the benefits and limitations of formal support received by caregivers.

Recommendations for Future Research

It is recommended that this study be replicated in other similar populations and in populations of individuals that experienced BI from ruptured aneurysms or

degenerative brain diseases. A larger sample size is necessary. Accessing caregivers belonging to all BI support groups in the province, as well as several institutions would increase the number of respondents. Financial burdens should be included in future studies. It is important that in future studies depression be considered as a possible outcome of burden. Further testing of several scales used in this study, such as those used to measure cognitive status, behavioral status, and ability to perform ADL, would be useful to identify whether they are appropriate for use as screening tools by nurses in the community or in outpatient departments. Other possible predictors are caregivers' health status, caregivers' depression, caregivers' difficulties accessing information, or formal social support. Measuring the burdens other family members experience is also recommended. A longitudinal study of caregivers of survivors of BI would be most beneficial, particularly to identify difficult periods of adjustment between institutions or from the institutions to the community. Further research in this area may suggest other nursing implications.

Summary

Findings were discussed in relation to other studies of caregiver burden. The response from recipients to the study was reviewed. Limitations of the study and recommendations for further research were discussed.

VI. Summary, Conclusions, and Nursing Implications

The findings and the conclusions are summarized in the following paragraphs. Implications for nursing practice are also discussed.

Summary of Findings

The findings of the study are reviewed in order of the research questions. The level of burden experienced by the caregivers was moderately low at 66.9, on a scale of 0 to 100. Developmental burden was rated the greatest burden, and emotional burden was rated the lowest type of burden experienced by the caregivers. The one predictor of the caregivers' total burden was frequency of problematic behaviours on the part of the survivor. The only statistically significant predictor of physical burden was caregivers' perceived informal social support.

The second question regarding the relationship between characteristics of the caregivers (caregivers' age, relationship to survivor with a BI, and caregivers' place of residence) and caregiver burden was not supported. The third question was also not supported. Time since the BI was not associated with total caregiver burden or any type of burden.

In relation to the fourth question, cognitive status of the survivor was correlated with caregiver burden. Specifically, low cognitive status was related to high burden. Also cognitive status of the survivor was related to time dependency burden, developmental burden, and physical burden. The frequency of the survivors' problematic behaviours was significantly related to total caregiver burden. Increased

frequency of the survivors' behaviours was correlated with four kinds of caregiver burden. These kinds of burdens were time dependency, developmental, physical, and emotional burden.

With respect to the fifth question, the inability of survivors to perform ADL was found to be significantly related to total caregiver burden. Survivors' inability to perform ADL was correlated with time dependency, developmental, and physical burden.

The sixth question, informal social support of the caregivers was significantly related to total caregiver burden, time dependency burden, developmental burden, physical burden, and social burden. As expected, greater informal social support was associated with less burden.

Conclusion

The total burden of caregivers in this sample was moderately low. Developmental burden had the highest rating and emotional burden had the lowest rating. The kinds of burdens identified in this study present a clearer picture of the caregivers' burdens than does the total burden score. While the results of this study are not generalizable to any other population, the survivors' cognitive status, behavioral status, and inability to perform ADL are significantly related to the concept, caregiver burden. Also, the caregivers' increased perceived informal social support was related to decreased caregiver burden.

Implications for Nursing Practice

Several nursing implications are suggested from the findings of this study. First, it is suggested that nurses become very familiar with the survivors' behaviours and cognitive abilities as well as with caregivers' needs, so that they can plan appropriate nursing interventions. The caregivers' perspectives of the survivors are very important to consider in any nursing care planning because the survivors, themselves may lack insight because of their injuries. As the caregiver increasingly assumes responsibility for the caregiving of the survivor, it is also recommended that the nurse facilitates the caregivers abilities to learn caregiving strategies. The benefits of formal social support have been not been adequately recognized. Accurate assessment of the family's needs and early clinical intervention may prevent maladaptive patterns of coping on the part of the caregiver (Rolland, 1984).

A partnership is necessary between the nurse and the caregiver (Hirschfeld, 1983; Nolan & Grant, 1989). It is suggested that strategies and skills for the caregiver are taught within a partnership relationship because caregivers' positive behaviours can be assessed and integrated into the nursing interventions. A thorough assessment of the caregiver may identify positive coping strategies and nurses may be able to capitalize on these strategies or strategies that enable survivors of BI to relearn ADL could be taught to the caregivers. As well, nursing strategies used to deal with survivors' difficult behaviours could to be taught to the caregiver. Assertiveness skills may also assist the caregivers of survivors' of BI in dealing with difficult behaviours.

Nurses in all areas of practice need to be aware of the signs and symptoms of clinical depression that may be experienced by some caregivers and survivors of BI. A serendipitous observation was the report of a few suicides or attempted suicides of survivors. Nursing interventions for clinical depression for both the caregivers and the survivors are extremely important.

Summary

In order to plan effective interventions to assist caregivers of survivors of BI, nurses must have a thorough understanding of the complexities of the concept, caregiver burden. This study has identified additional research questions and several possible implications for nursing practice. Further research in this area will help to identify the nursing strategies that are most effective in reducing caregiver burden.

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Appendix A

Letter to Members of Brain Injury Support Groups

February 1992,

Dear Caregiver,

Since 1982, I have worked as a nurse caring for people with head injuries. I am presently working on a Master of Nursing degree. Caring for someone who has had a head injury can be difficult at times. I am interested in studying the caregiver of an adult with head injuries. **Your response is very important in understanding what caregiving of a relative/friend with a head injury is like.**

The survey is enclosed. It contains information about you, the person you care for, and your experience. There are no right or wrong answers.

The survey:

- examines your feelings about giving care to your relative or friend with a head injury.
- is voluntary.
- will take 30 to 45 minutes to complete.
- will be mailed out by the brain injury support groups. Your name is unknown to me.
- no individuals will be named in the results.
- information will be kept on a computer file with no names.
- will not help you directly.
- the information from this survey may help families in the future.
- written results will be sent to the brain injury support groups and the Department of Health.

Please send me a note separate from the survey if you would like the results. You may contact me or my supervisor with any questions. Thank you for your time.

Sincerely,

Agnes Mitchell
Faculty of Nursing
3rd Floor Clinical Sciences Building,
University of Alberta,
Edmonton, Alberta. T6G 2G3
Phone: 433-5255

My supervisor: Dr. Anita Molzahn
Associate Professor, Faculty of Nursing,
Phone: 492-6279

Appendix B

Thank You Letter to Members of Brain Injury Groups and Respondents from Advertisements

February 1992

Dear Caregiver,

Thankyou for the time you spent filling out the survey for FAMILY CAREGIVERS OF ADULT SURVIVORS OF HEAD INJURIES. **Your participation is very valuable. If you have not filled out the survey it is not too late to do so.** Your response is most important in understanding the experience of caring for a person with a head injury. Results will be sent to the brain injury support groups, and the Department of Health in about six months.

Thankyou,

Sincerely,

Agnes Mitchell

Faculty of Nursing
3rd Floor Clinical Sciences Building,University of Alberta,
Edmonton, Alberta. T6G 2G3

My supervisor: Dr. Anita Molzahn
Associate Professor,
Phone: 492-6279

Appendix C

Advertisement

BRAIN INJURY SURVEY

Are you caring for a family member or friend who has survived a **head/brain injury**? If you are willing to complete a survey about your present experience, phone or write:
AGNES (a nurse and a graduate student)
403-433-5255,
FACULTY OF NURSING, UNIVERSITY OF ALBERTA,
3RD FLOOR CLINICAL SCIENCES BUILDING, EDMONTON, T6G 2G3

Appendix D

Letter to Respondents from Advertisements

March 1992,

Dear Caregiver,

Thankyou for responding to the ad in the newspaper. Since 1982, I have worked as a nurse caring for people with head injuries. I am presently working on a Master of Nursing degree. Caring for someone who has had a head injury can be difficult at times. I am interested in studying the caregiver of an adult with head injuries. **Your response is very important in understanding what caregiving of a relative/friend with a head injury is like.**

The survey is enclosed. It contains information about you, the person you care for, and your experience. There are no right or wrong answers.

The survey:

- examines your feelings about giving care to your relative/friend with a head injury.
- is voluntary.
- will take about 30 to 45 minutes to complete.
- no individuals will be named in the results.
- information will be kept on a computer file with no names.
- will not help you directly.
- the information from this survey may help families in the future.
- written results will be sent to the brain injury support groups and the Department of Health.

Please send me a note separate from the survey if you would like the results. You may contact me or my supervisor with any questions. Thank you for your time.
Sincerely,

Agnes Mitchell
Faculty of Nursing
3rd Floor Clinical Sciences Building,
University of Alberta,
Edmonton, Alberta T6E 2G3
Phone: 433-5255

My supervisor: Dr. Anita Molzahn,
Associate Professor,
Faculty of Nursing,
Phone: 492-6279

Appendix E

Survivors Characteristics

The beginning questions are **about the relative/friend** with a head injury for whom you care. Remember, there are no right or wrong answers. Please do not write any names on this survey. Please make an X on the line or fill in the blank.

Sex: Male ___ Female ___

Present age in years: ____

Date of Accident or Incident: Month _____ Year ____

Cause of Head Injury:

Car Accident _

Motorcycle Accident _

Accident at work _

Accident during recreation _

Aneurysm _

Stroke _

Result of Violent Act _

Suicide Attempt _

Other Please Specify _____

Was your relative/friend in a coma (Coma means not obeying commands, not uttering words, and not opening eyes)?

Yes ___ No ____

If yes, for how long?

_____hours, _____days, _____weeks, _____months.

How long was your relative in an acute care hospital?

_____days, _____weeks, _____months

Was your relative/friend transferred to a rehabilitation hospital?

Yes ___ No ___

If yes, how long was your relative/friend in the rehabilitation hospital?

____ weeks, ____ months, ____not applicable

Has your relative/friend experienced seizures since the injury?

Yes ___ No ___

If yes, are their seizures controlled by medications?

Yes ___ No ___ not applicable ___

Is your relative/friend currently working? (this includes work outside the home, housework, child care, and volunteer work)

Yes ___ No ___

Is the kind of work the same as prior to the injury?

Yes ___ No ___ not applicable ___

If no, please explain

_____

_____

_____

_____

Is your relative/friend doing the same amount of work as prior to the injury?

Yes ___ No ___ not applicable ___

Appendix F

Caregivers Characteristics

These questions are about you and your caregiving situation.

Your age in years: _____

Sex: Female _____ Male_____

Your relationship to the person with a head injury:

Mother ___

Father ___

Wife/Commonlaw Wife ___

Husband/Commonlaw Husband ___

Sister ___

Brother ___

Grandmother ___

Grandfather ___

Friend ___

Specify Other Please: _____

Your Marital Status:

Never Married ___

Married ___

Common Law ___

Divorced ___

Separated ___

Widowed ___

Please indicate your total, before tax, household income for 1991 (Please include all sources of income ie: wages, pensions, interest for all family members):

< - $15,999 ____

$16,000 - $30,999 ____

$31,000 - $50,999 ____

$51,000 - $70,999 ____

> - $70,000 ____

How many years of formal education have you completed?

High School ____ years

Vocational/Technical/Community College ____ years

University ____ years

Do you hold a job other than caring for your relative/friend?

Yes ___ No ___

If, yes: Fulltime Job ___

Part-time Job ___

Do you live with your relative/friend in the same residence?

Yes ____ No ____

If no, is your relative/friend:

living independently ____

living independently but requires some outside assistance ____

living with others (group home, another family, friends) ____

in a long term hospital ____

in a rehabilitation hospital ____

in an acute care hospital ____

Do you belong to any Support Group or association for families living with the effects of brain injury?

Yes ____ No ____

Now I would like to ask you some more questions about your support.

Is there someone who helps you look after your relative/friend on a **regular** basis, for example, who stays with (him/her) or who helps (him/her) do things on a daily basis?

Yes ____ No ____

Appendix G

Cognitive Status Scale

Please make one X in each row that best represents the abilities of your relative/friend. The following questions relate to your relative's memory and the difficulty he or she may have doing some things. Please indicate the amount of difficulty your relative/friend has in the following areas:

HOW DIFFICULT IS IT FOR YOUR RELATIVE/ FRIEND TO:	**CAN'T DO AT ALL**	**VERY DIFFICULT**	**FAIRLY DIFFICULT**	**JUST A LITTLE DIFFICULT**	**NOT AT ALL DIFFICULT**
state his/her name					
state the day of the week					
state the year					
name the prime minister of Canada					
remember a short message or phone number for a few minutes					
remember what he/she has done in the past day					
remember to complete a task (turn off the stove, get items at the store)					
remember his/her address					
recognize people that he/she knows					

HOW DIFFICULT IS IT FOR YOUR RELATIVE/ FRIEND TO:	CAN'T DO AT ALL	VERY DIFFICULT	FAIRLY DIFFICULT	JUST A LITTLE DIFFICULT	NOT AT ALL DIFFICULT
find his/her way around the block (if in a town or city) or the yard (on a farm)					
understand simple instructions					
speak sentences					
solve a simple problem					
follow two requests without help from you					
state his/her desires or wants					
tell the time					
think clearly					
keep his/her attention on an activity for 15 minutes					
start at the number 100 and subtract 7, and 7 again, and 7 again					
add the numbers 26 and 50					

Adapted from: Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30, 583-594.

Appendix H

Behavioral Status Scale

The following behaviours are common among adult survivors of head injuries. In the past week, on how many days did you **personally** have to deal with the following behaviour of your relative/friend? **PLEASE MAKE ONE X IN EACH ROW.**

ON HOW MANY DAYS DID HE/SHE	5 OR MORE DAYS	3 - 4 DAYS	1 - 2 DAYS	NO DAYS
Keep you up at night				
Repeat questions/stories				
Try to dress the wrong way				
Have a bowel or bladder "accident"				
Hide belongings and forget about them				
Cry easily				
Act depressed or downhearted				
Cling to you or follow you around				
Become restless or agitated				
Become irritable or angry				
Swear or use foul language				
Become suspicious or believe someone is going to harm him/her				
Threaten violence towards others or yourself				
Display childish behaviour				
Becomes tired very easily				
Have no control over alcohol intake				
Complain about their physical condition				
Complain about their living situation				
Show sexual behaviour or interests at the wrong time or place				

Adapted from: Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30, 583-594.

Appendix I

Ability to Perform ADL

PLEASE MAKE ONE X IN EACH ROW.

HOW MUCH DOES YOUR RELATIVE/FRIEND DEPEND ON YOU FOR:	COMPLETELY	QUITE A BIT	SOMEWHAT	NOT AT ALL	NOT APPLICABLE
eating					
bathing/ showering					
going to the bathroom					
dressing /undressing					
brushing teeth/hair					
handling money					
getting in/out of bed					
moving around the house					
driving or taking the bus to where (he/she) needs to go					
going for a walk in the neighbourhood					
taking medications					
using the telephone					
doing housework like sweeping floors/dusting					
getting going in an activity					
cooking/ preparing food					

L. Pearlin (personal communication, August 1991).

Appendix J

Informal Social Support

Let's now turn to the help and support you get from your friends and relatives. Think about your friends and family, other than the adult survivor. **PLEASE MAKE ONE X IN EACH ROW.**

PLEASE INDICATE THE EXTENT TO WHICH YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENTS:	**STRONGLY AGREE**	**AGREE**	**DISAGREE**	**STRONGLY DISAGREE**
There is really no one who understands what I am going through				
The people close to me let me know that they care				
I have people a friend or relative in whose opinions I have confidence				
I have someone who I feel I can trust				
I have people in my life who make me feel good about myself				
I have a least one friend or relative I can really confide in				
I have at least one friend or relative I want to be with when feeling down or discouraged				
I have people around me who help me to keep my spirits up				

Pearlin, L., Mullan, J., Semple, S., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30, 583-594.

Appendix K

Caregiver Burden Inventory

Now I would like to know how you see your experience as a caregiver and what your feelings are about giving care. Think of your experiences as a family caregiver. How well does each of the following statements describe your experience in caring for your relative/friend in the past month? PLEASE MAKE ONE X IN EACH ROW.

	STRONGLY AGREE	AGREE	NO OPINION	DISAGREE SOMEWHAT	STRONGLY DISAGREE
My relative/friend needs my help to perform many daily tasks.					
My relative/friend is dependent on me.					
I have to watch my relative/friend constantly.					
I have to help my relative/friend with many basic functions.					
I don't have a minute's break from my caregiving chores.					
I feel that I am missing out on life.					
I wish I could escape from this situation.					
My social life has suffered.					
I feel emotionally drained due to caring for my relative/friend.					
I expected that things would be different at this point in my life.					
I'm not getting enough sleep.					
My health has suffered.					
Caregiving has made me physically sick.					
I'm physically tired.					

	STRONGLY AGREE	AGREE	NO OPINION	DISAGREE SOMEWHAT	STRONGLY DISAGREE
I don't get along with other family members as well as I used to.					
My caregiving efforts aren't appreciated by others in my family.					
I've had problems with my marriage.					
I don't do as good a job at work as I used to.					
I felt resentful of other relatives who could but do not help.					
I feel embarrassed over my relative/friend.					
I resent my relative/friend					
I feel uncomfortable when I have other friends over.					
I feel angry about my interactions with my relative/friend.					
I feel ashamed of my relative/friend.					

DO YOU HAVE ANY FURTHER COMMENTS THAT WOULD ENABLE ME TO UNDERSTAND YOUR CAREGIVING EXPERIENCE?

Novak, M., & Guest, C. (1989a). Application of a multidimensional caregiver burden inventory. The Gerontologist, 29, 798-803.